

Moving Past The Pandemic

Considerations for Autistic Children and their Caregivers Across Canada

May 26, 2022

A conversation with Drs. Janet McLaughlin, Vivian Lee,
and Jonathan Weiss



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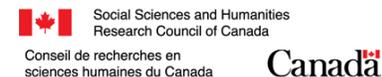
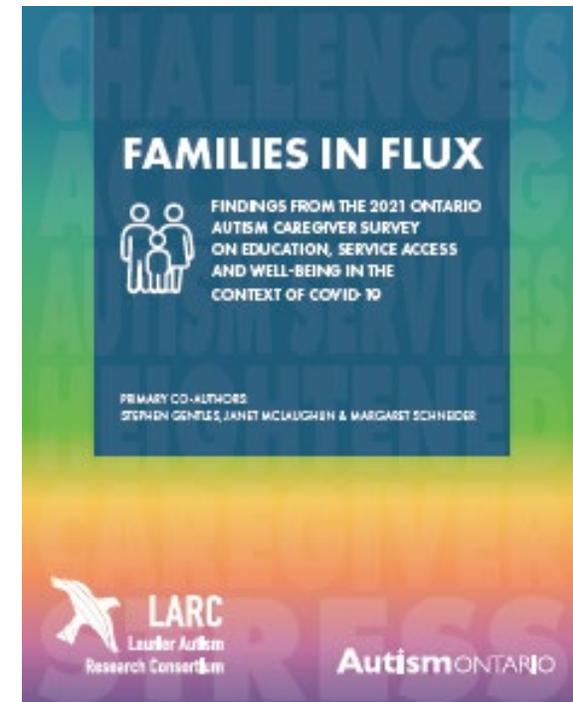
How did Ontario autistic families fare during the pandemic?



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Purpose

To hear from primary caregivers of Ontario children or youth with an autism diagnosis aged 17 years or younger about their recent experiences in the context of the COVID-19 pandemic.





2,685 caregivers

2,933 children diagnosed with autism

90% of caregivers were female



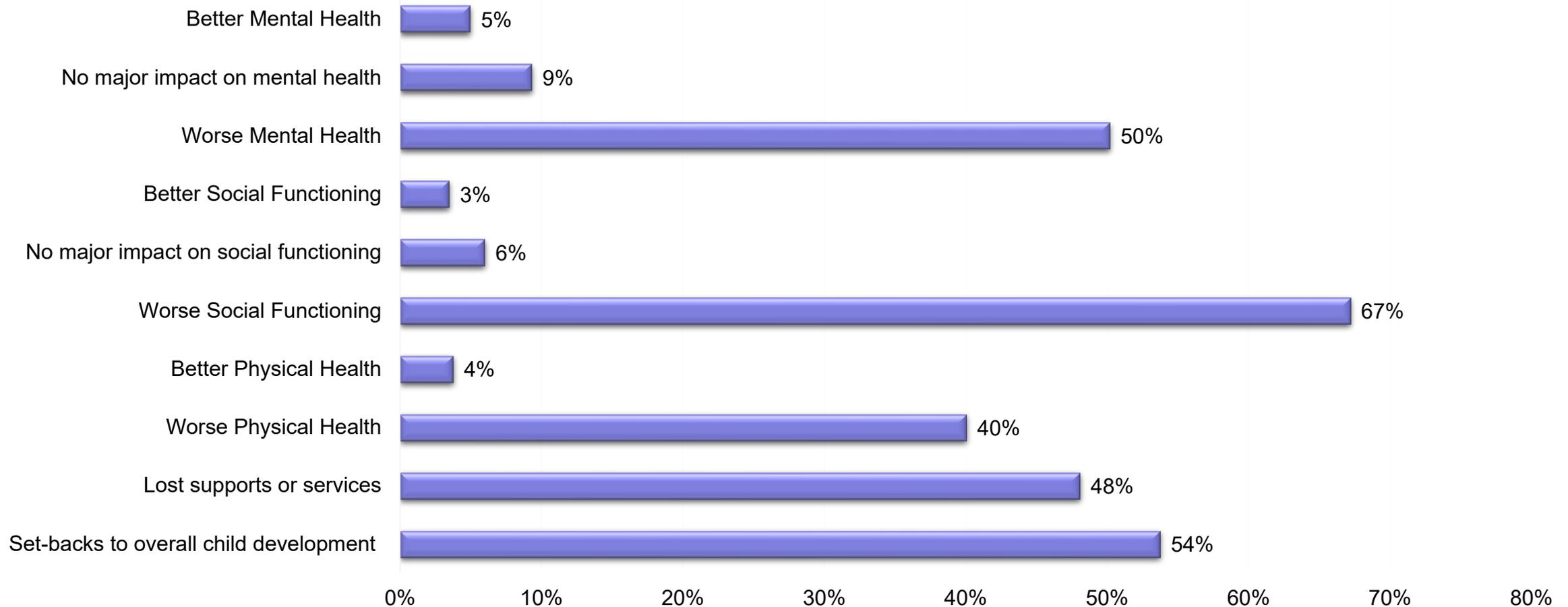
26% of children missed 21 or more weeks of in-person school attendance for any reason over the 2020-2021 school year.



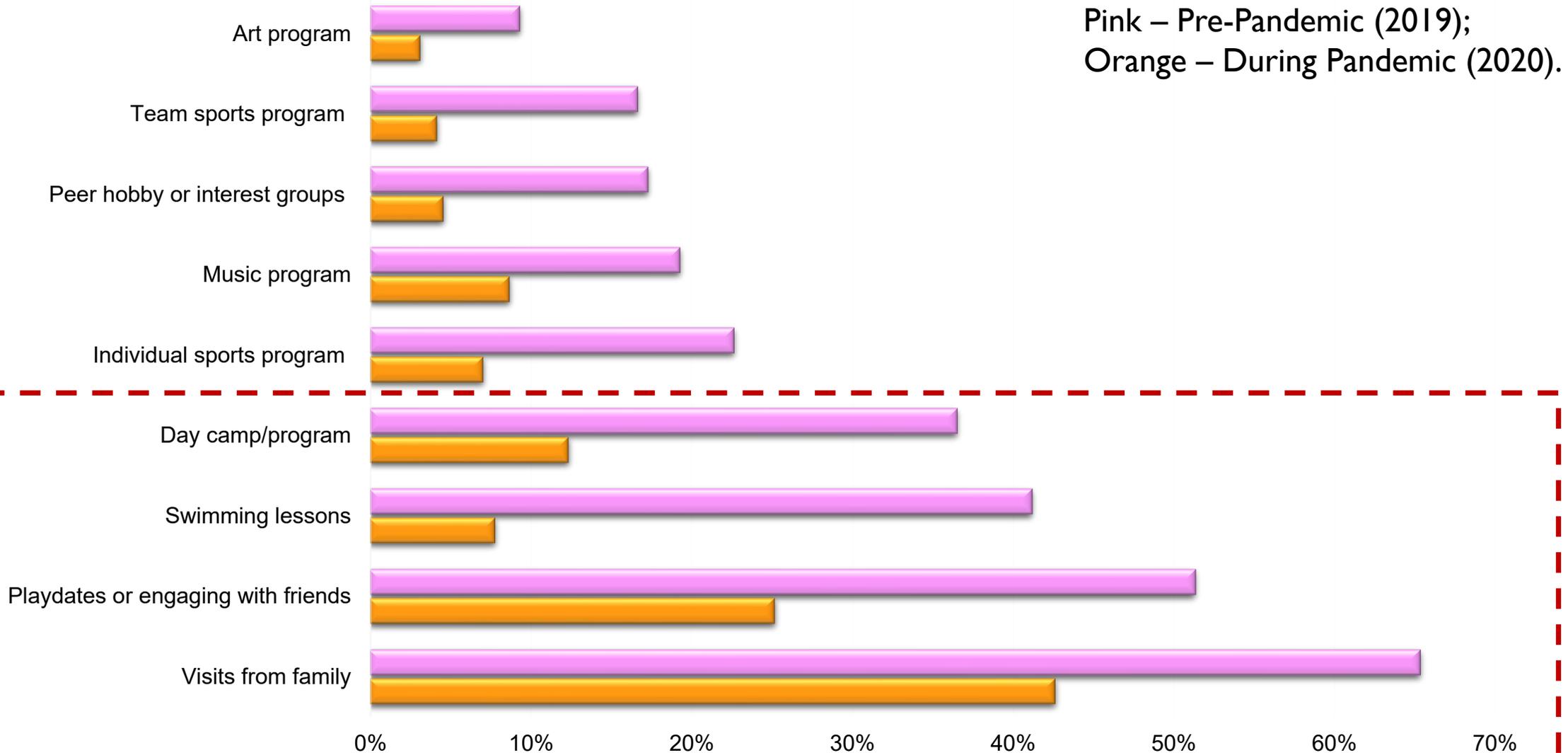
“In person would have been ideal. He needs that structure and routine that school provides. I felt that he fell through the cracks of the school system even more than usual during the shutdowns.”



Impacts of the April-June 2021 School Shutdowns



Recreation Changes During Pandemic

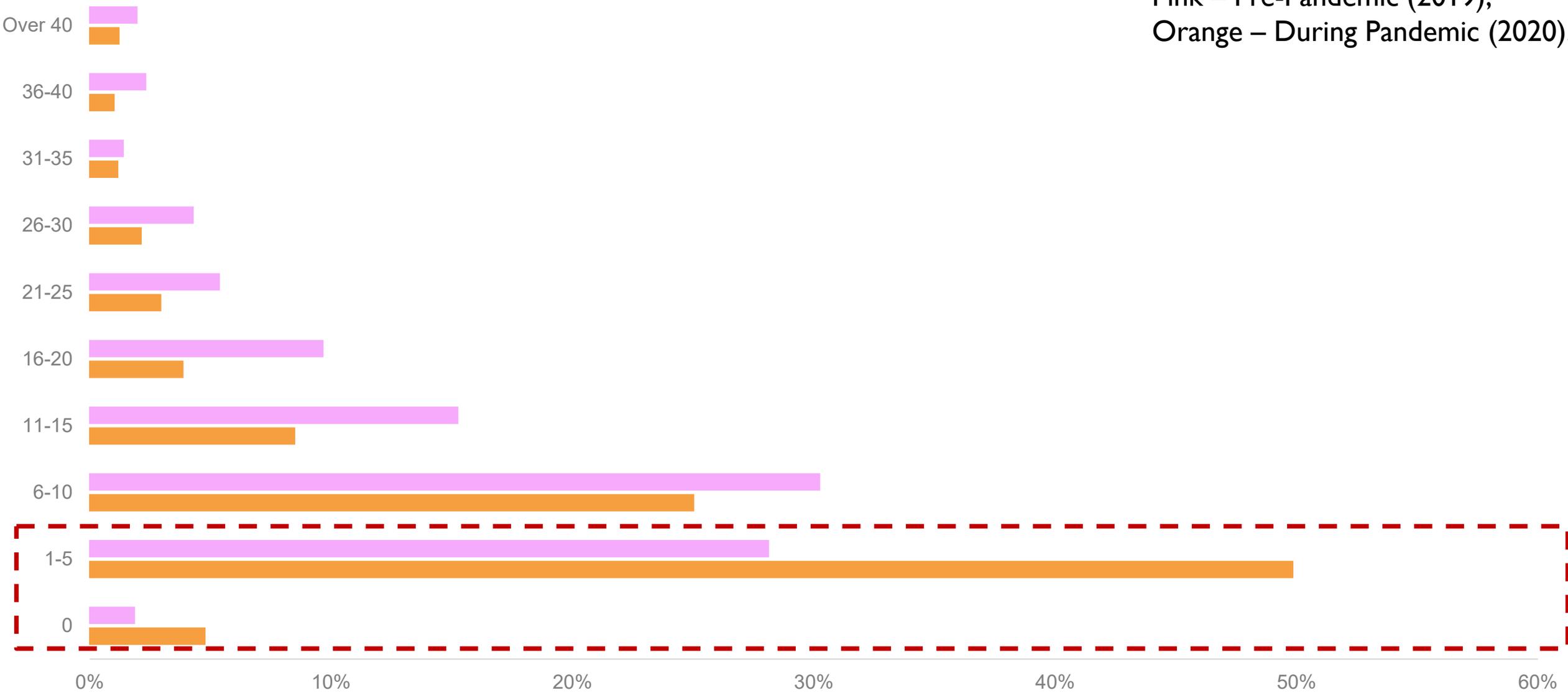


“It has been very difficult that everything is closed for recreation (swimming pools, drop in programs) that we heavily rely on. It was a full time job to keep my child active and engaged despite these closures.”

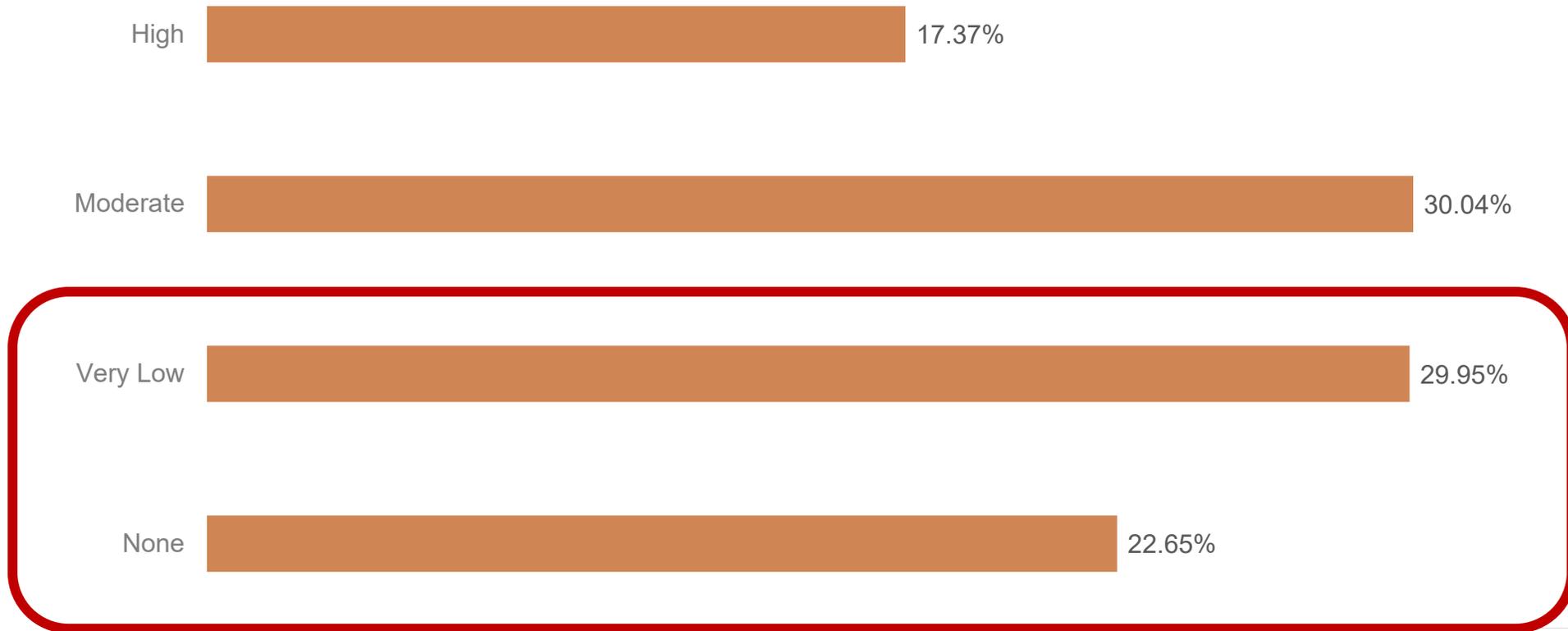


Hours of Weekly Physical Activity

Pink – Pre-Pandemic (2019);
Orange – During Pandemic (2020).



OAP Meeting Child's Needs?



“Wait lists (for speech therapy) are about 1.5 years, which means using the one-time funding is not an option, since it will expire...before we get in.”

“I have never gotten support on how to even navigate the support. So overwhelming I said forget it and just survived.”



“His window of “early intervention” was lost waiting...”

Caregiver – Level of Stress/ Crisis

Marked	8.4%
Moderate	56.0%
Mild	35.6%

*Using the Brief Family Distress Scale: “On a scale of 1 to 10, please indicate where you and your family currently are right now, in terms of crisis.” Mild: 1-3, Moderate: 4-6; Marked: 7-10. **Reference:** Weiss, J.A., & Lunsky, Y. (2010). The Brief Family Distress Scale: A Measure of Crisis in Caregivers of Individuals with Autism Spectrum Disorders. *Journal of Child and Family Studies*, 20(4), 521–528. <http://doi.org/10.1007/s10826-010-9419-y>



Caregiver Level of Stress/ Crisis

Multiple demands such as childcare, work

Demands related to availability, navigation or accessibility of autism services

Autism-related concerns affecting the child

COVID-related challenges

Economic stresses such as personal finances, employment, difficulty affording services

Physical or mental health challenges

Resilience or coping strategies

Need for respite, social support, or time to themselves

Urgent care services or mental health crises

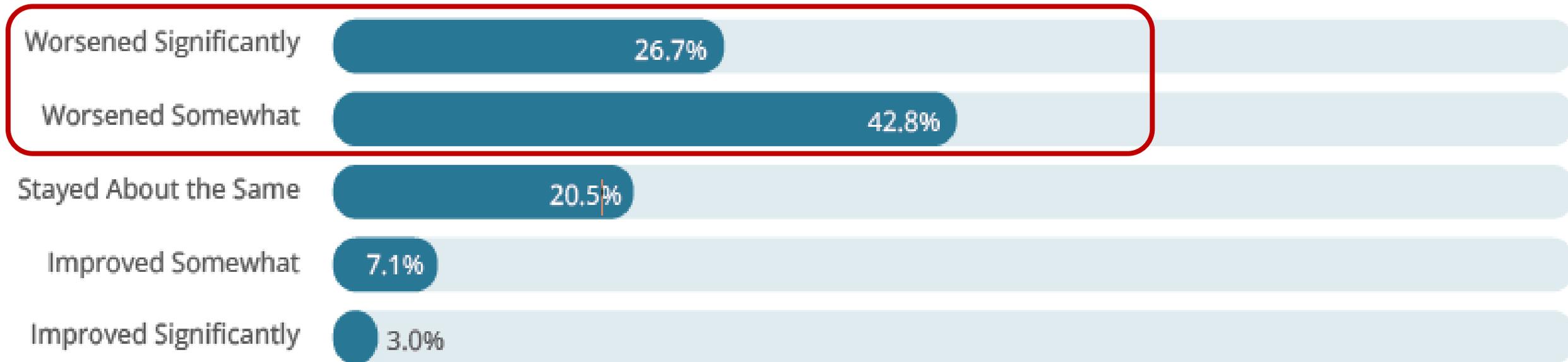
“I don’t know what to do. I don’t know who to talk to. There is no help from my son’s school. I am lost.”

“When we are struggling...it isn’t fun to reach out and someone tell you **there is no help and that the wait list is 6 months to a year.... I have dealt with anxiety and days of crying and struggling and begging with **no one and no answers.**”**



How Caregiver Mental Health Changed During the COVID-19 Pandemic

HOW CAREGIVER MENTAL HEALTH CHANGED DURING THE COVID-19 PANDEMIC (*n*=2,561)



“**Constantly juggling demands** for multiple children doing remote and trying to work remote. **Absolutely exhausting.**”

“Child needs a lot of support and during Covid we (parents) had to be a little bit everything: **parents, teachers, and therapists.**”

“As I'm the main caregiver most of my time goes to her, from 7:00am-8:30 pm, then anything that arises during the night, **many many sleepless nights.**”



“Working full time from home and trying to help two kids with online learning was stressful and made for extremely long days.
Hard to find time for self-care...”

“Being in and out of school due to COVID lockouts, then completely shut out of school since April 12 has taken an **emotional toll** on me. My child going to school daily was my respite and her need for autism support.”



Caregiver Mental Health – Autism-Related Care:

Extremely Affected

28.3%

Very Affected

31.3%

Somewhat Affected

27.0%

Slightly Affected

10.8%

Not at All Affected

2.7%



“Time is passing... I see my kids growing and missing all the learning opportunities they should be provided with to help them develop. I see forever waitlists. It is heartbreaking and so frustrating. I cry every day...”

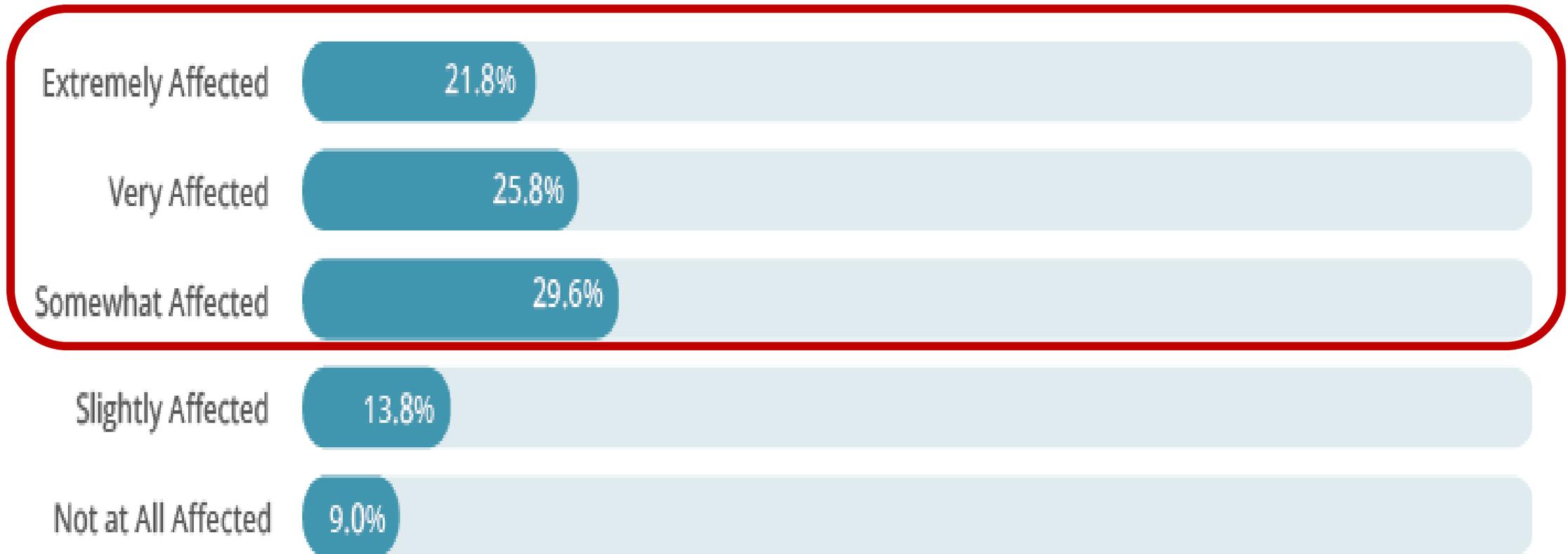


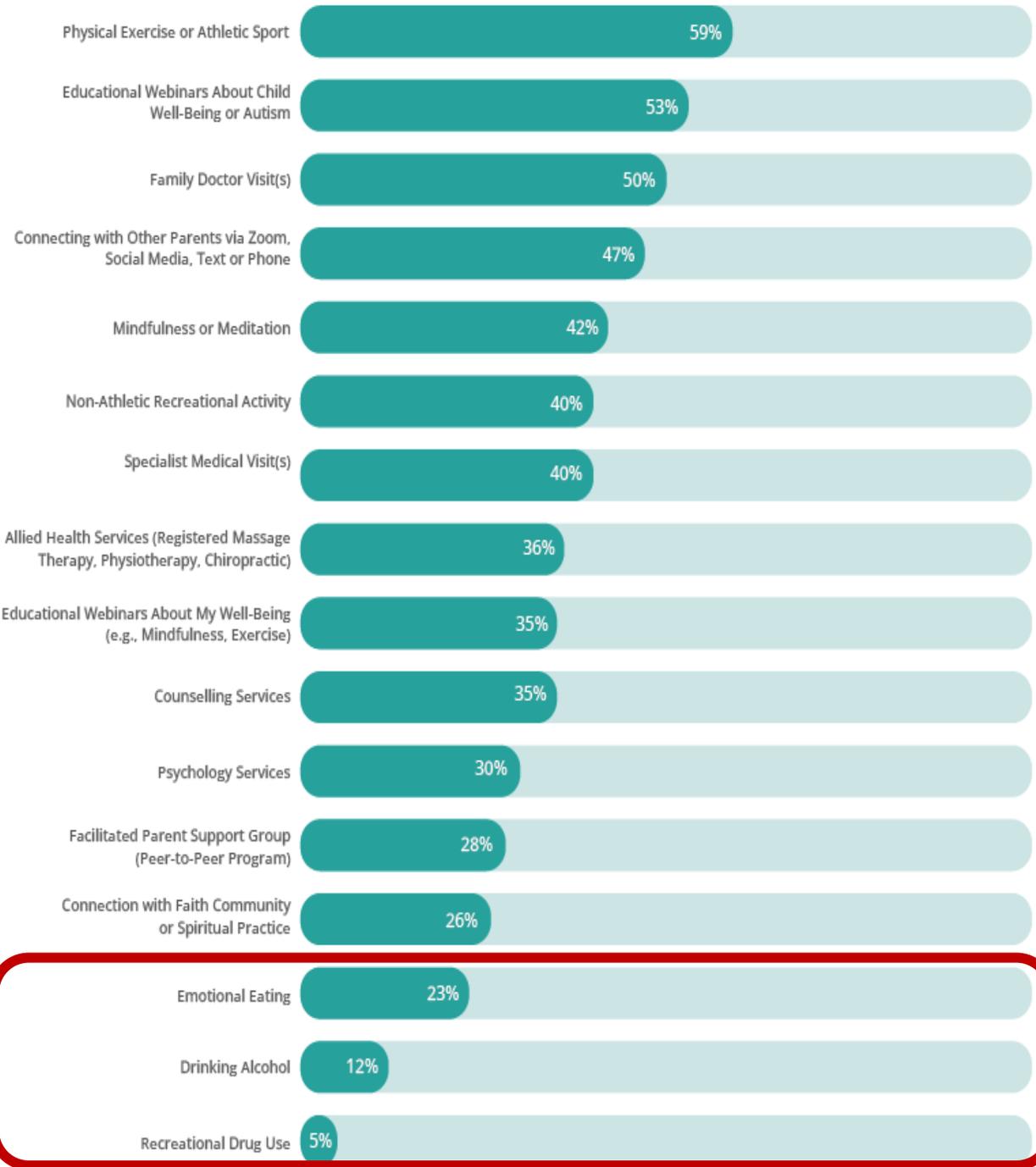
“The advocacy piece is **truly exhausting and heartbreaking**. Research tells us what kids need, yet as a parent I have to fight every single day for my son to get a **fraction of what he needs.**”

“Advocating for 2...children is a full time job and parenting them is **another full time job**. I have **zero time** for anything else.”



Caregiver Physical Health





Summary of Challenges Facing Families

- In a climate of **limited capacity resources**, advocacy is a full-time job
- **Time constraints** (giving up sleep, work, personal time, etc.)
- **Financial pressures** during long waitlists
- **Constant stress**: mental, emotional and physical well-being consequences



Caregivers Overwhelmingly Expressed:

- Extreme **frustration** over **long wait-times**
- **Disillusionment and distrust** of the government
- **Lack of knowledge of services or service navigation**
- **Frustration** over the **time and energy** they must spend to **advocate for and navigate services**
- Belief that **OAP** supports are critical for their child's development and well-being, and that they are **urgently needed**



Conclusions

- **Stressors that existed pre-pandemic** (related to autism navigation and access) **remained present and worsened during the pandemic**
- **COVID educational disruptions** impacted both children and caregivers
- **OAP funding** was welcome and sufficient for some families, while for others it was a 'drop in the bucket'
- Need to consider the **family** unit as an **eco-system**



When families thrive, children thrive.



When families and caregivers are supported to their potential, children can reach their potential



Acknowledgements



www.wlu.ca/LARC

Participating Families

Funders: Autism Ontario (Community Partner); Social Sciences and Humanities Research Council (SSHRC); A gift to LARC from the Dare family, in honour of the late Carl M. Dare

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How did the autistic families and service providers adapt?



Impact of COVID-19 on the Mental Health and Wellbeing of Caregivers and Families of Autistic People

A Rapid Synthesis Review

Prepared by

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For

The Canadian Institutes of Health Research

Received: 8 April 2021 | Accepted: 10 September 2021

DOI: 10.1002/aur.2616

REVIEW ARTICLE

The impact of COVID-19 on the mental health and wellbeing of caregivers of autistic children and youth: A scoping review

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- Conducted a rapid review of the literature on the impact of the pandemic on the mental health and wellbeing of families
- **Find evidence-based mental health supports and interventions that have emerged in response to *family service needs* during the pandemic**



What we found...

- Services provided at-home kits for parents to administer (Lee et al, 2021)
- Families and services adapted by using phone or web-based technology to continue essential programs and services
 - Behavioural Supports
 - Speech and language services
 - Mental Health Services

But how effective?

Secret Agent Society- Operation Regulation

Use an explanatory mixed-methods approach to:

1. Explore the acceptability, feasibility, and clinical utility of the adapted online version of SAS:OR within *the context of a pandemic*
2. Explore strengths and challenges of a remote emotion regulation program for autistic children



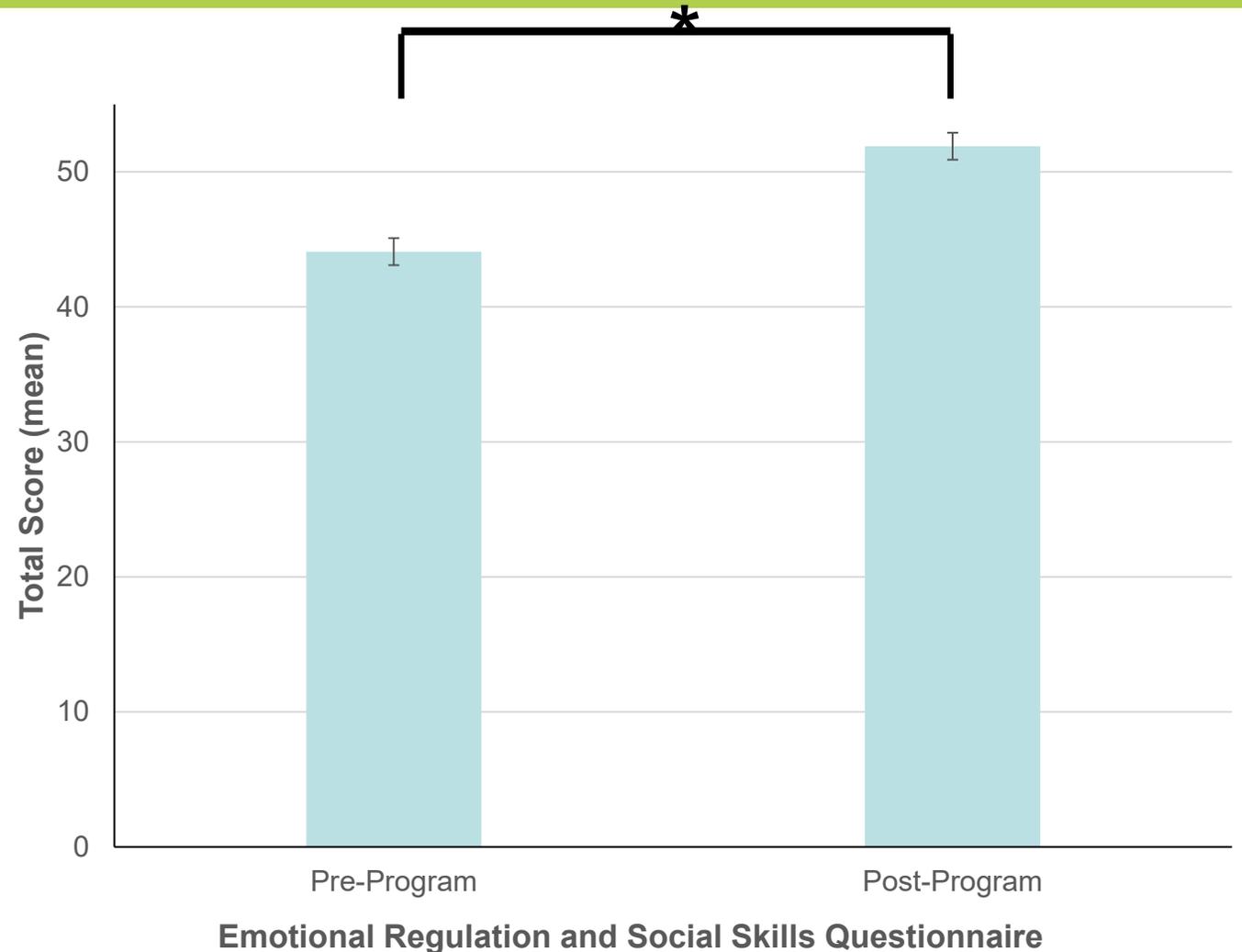
What we Found...

Child Outcomes:

- No significant difference in pre- and post-program internalizing and externalizing scores
- Significant increase in parent-reported emotion regulation and social skills $t(10) = 2.89$, $p=0.03$, $d=0.84$)



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Program Acceptability

Item	Median(SD) and Range
1. I feel positively about this program	5.0 (0.68), 3-5
2. The amount of effort required to do this program was acceptable	5.0 (0.68), 3-5
3. This program aligned well with my values	5.0 (0.80), 3-5
4. I understood this program and how it works	5.0 (0.82), 3-5
5. I did not need to give up resources or opportunities in order to participate in this program	4.0 (0.87), 3-5
6. This program was effective in achieving its goals	4.0 (1.16), 1-5
7. I am confident in my ability to use the skills I learned in this program	4.0 (0.75), 3-5

- **Implementation Acceptability Scale**

- Overall, parents report high acceptability
- 90% reported that the program helped achieve their goal (for child)
- BUT not every family and/or child benefited!
 - Require technology knowledge and access
 - Difficult for younger children and/or those with attentional and behavioural challenges

Findings from Therapists...

- Therapists reported building rapport with parents and children by incorporating *individualized care*

“Overall, I feel like I was able to build rapport, and at the end, our relationship was comparable to what I think we would have had in person.”

- Therapists recommended several approaches for managing challenging behaviours online

“..I constantly told him how brave I thought he was for doing this online, and he really connected with that”

Findings from Therapists...

Therapists reported implementing treatment modifications to provide optimal care

“..I just think having the flexibility and picking and choosing what works best for [CHILD] was very helpful”



YORK UNIVERSITY **RECOMMENDATIONS FOR ONLINE INTERVENTION DELIVERY**
TIPS FOR WORKING WITH INDIVIDUALS ON THE SPECTRUM

Over the course of the COVID-19 pandemic, therapists have had to transition their services online and adapt interventions for their clients on the autism spectrum. Below are some tips to remember and incorporate before, during and after sessions that can promote positive outcomes

BEFORE SESSIONS

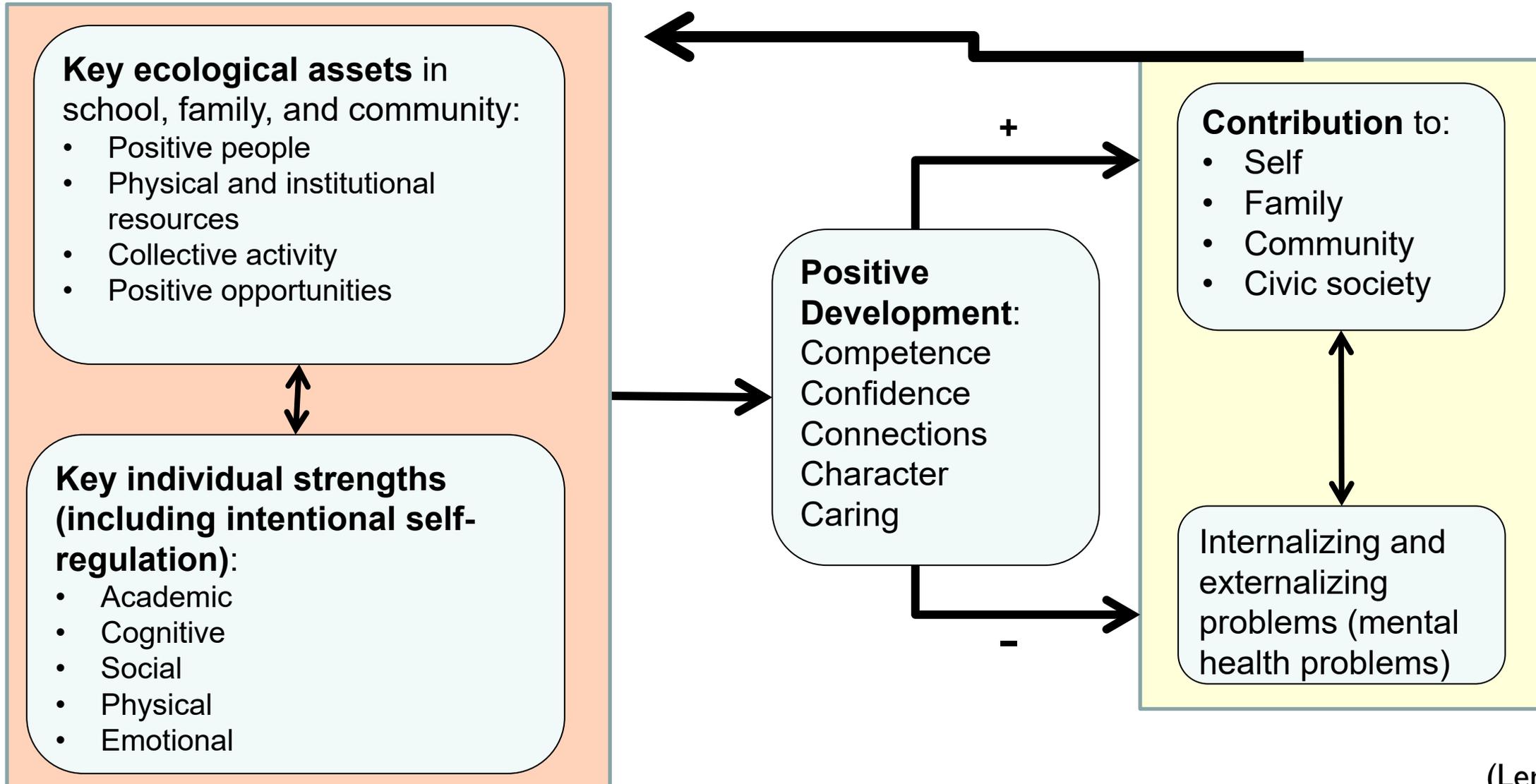
SETTING UP	SETTING UP
<ul style="list-style-type: none">Free your background from any personal items<ul style="list-style-type: none">Try using a virtual background or blur effect!Consider how you want to present yourself during the pandemic<ul style="list-style-type: none">What view of your room do you want your client to haveHow much you want to share about yourselfUse earphones for privacy	<ul style="list-style-type: none">Sit back at a distance from your cameraMimic the view your client(s) would have of you in personViewing a face up close may be uncomfortable for some clients
<p>ORIENTATION</p> <ul style="list-style-type: none">Ensure that your client(s) is in a safe and private space in their homeProvide a program overview<ul style="list-style-type: none">Review attendance policiesSet expectations for participation	<p>ORIENTATION</p> <ul style="list-style-type: none">Plan in advance for technological disruptionsHave a backup phone number on hand in case you get disconnectedBe patientProvide ample guidance and reassurance about technology use
<p>With Children</p> <p>Play a brief game to acquaint them with online interaction (for example, Kahoot quizzes)</p>	<p>A WORD ABOUT TECHNOLOGY</p> <p>Give your client(s) detailed instructions for technology use and discuss preferred methods and frequency of communication</p> <p>Zoom Tutorials → Click Here!</p> <p>Create unique and password-protected meeting links for each session</p>

How do we help autistic families move forward and strive?



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Thriving is a Cycle of Individual-Contextual Alignment

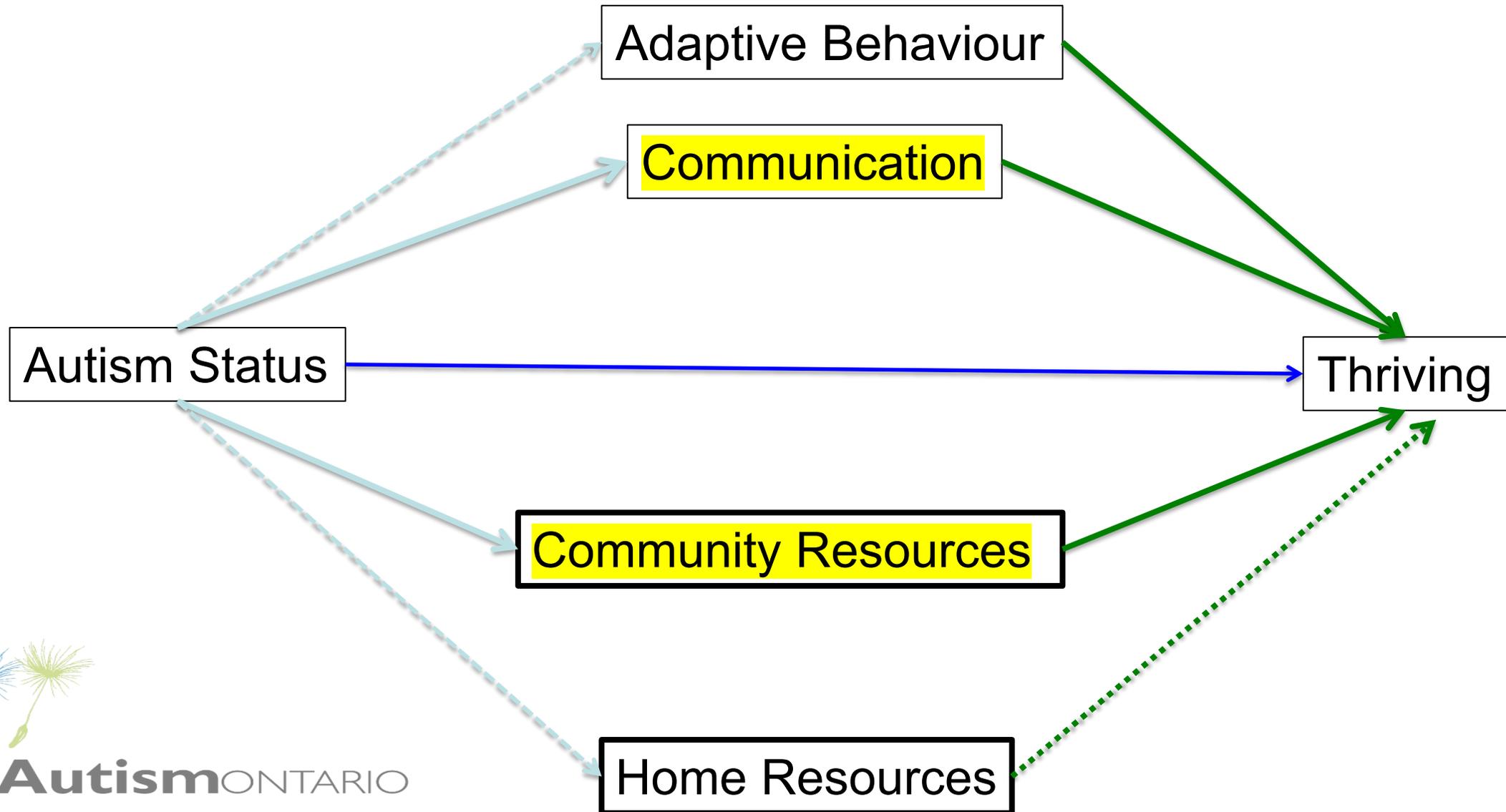


Positive Youth Development

- **Competence:** Positive view of one's actions in domain specific areas including social, academic, cognitive, and vocational.
 - *My child has the skills to succeed...*
- **Confidence:** An internal sense of overall positive self-worth and self-efficacy; one's global self-regard, as opposed to domain specific beliefs.
 - *My child believes that he/she can succeed*
- **Connectedness:** Positive bonds with people and institutions that are reflected in bidirectional exchanges between the individual and peers, family, school, and community.
 - *My child has positive relationships with...*
- **Caring:** A sense of sympathy and empathy for others.
 - *My child cares about other people...*
- **Character:** Respect for societal and cultural rules, possession of standards for behaviors, a sense of right and wrong (morality), and integrity.
 - *My child knows what is right and wrong...*

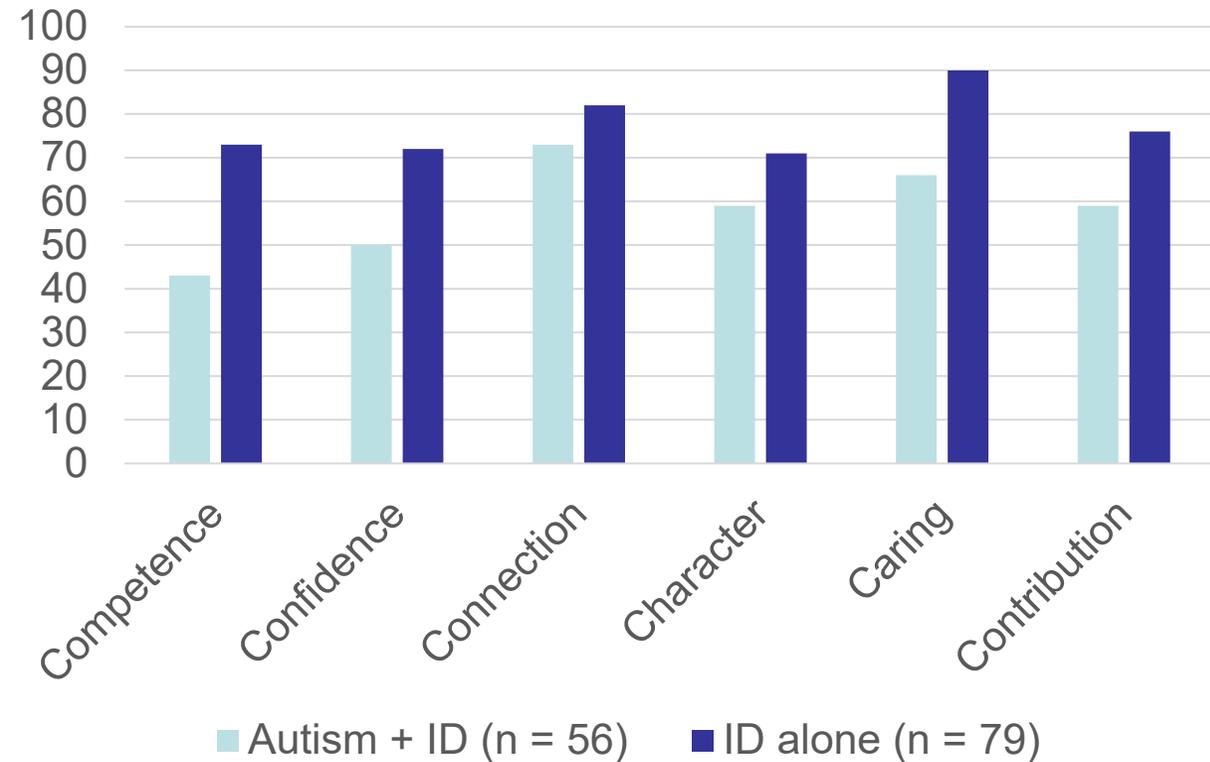


What Might Explain the Differences in Overall Thriving?



Many Autistic Children & Youth Can ‘Thrive’, But...

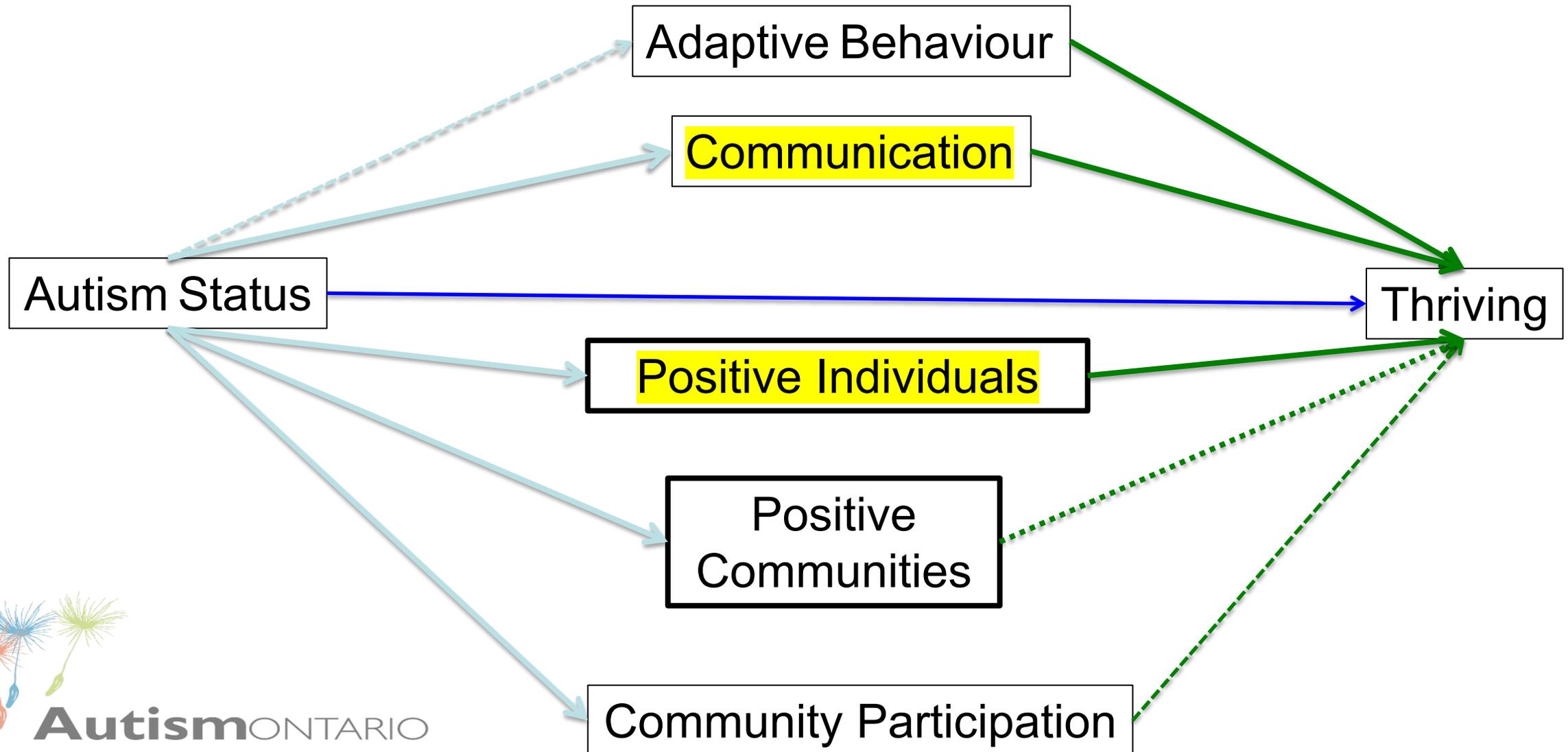
What percentage are ‘thriving’?



- **DURING THE PANDEMIC** (October 2021 to March 2022), we surveyed 135 parents of youth with developmental disabilities (12-30 years of age)
- What was related to overall parent reports of thriving?
 - Age
 - Independent skills
 - Communication skills
 - Home and community assets
 - Caregiver responsiveness
 - Family member support to the person
 - Community Participation: Person / family community participation
 - Positive individuals: Presence and involvement of positive caring people (e.g. mentors)
 - Positive community: The community is trustworthy and helpful, and works to support the person as well

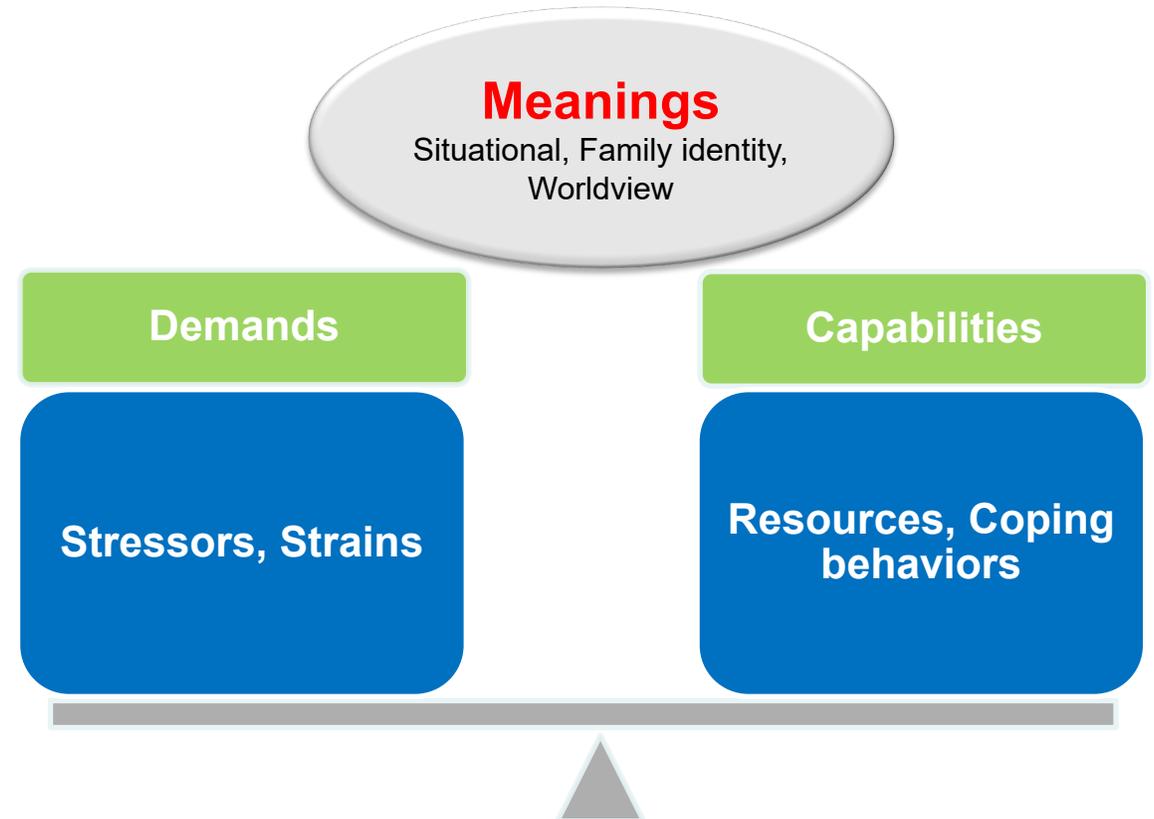


What Might Explain the Differences in Overall Thriving?



Supporting Families

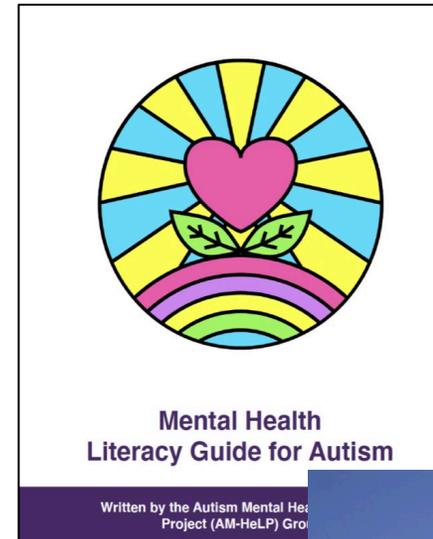
- Support caregiver responsiveness and resources
 - We have seen this strain and this resilience during the pandemic (Friesen, Weiss, Howe, et al., 2021)
- Where's the evidence?
 - Acceptance and Commitment Therapy Workshops (Blackledge & Hayes, 2006)
 - Mindfulness-based stress reduction (Lunsky et al., 2017; 2021)
 - Mindful Parenting (Singh et al., 2006)
 - Mindfulness Based Stress Reduction & Positive Empowerment Supports (Dykens et al., 2014)
 - MyMind: Concurrent mindfulness (Salem-Guirgis et al., 2019)



Family Adjustment and Adaptation Resource Model
(Patterson, 1988)

Creating Community Opportunities

- Provide youth with opportunities to build meaningful and supportive relationships with caring adults outside of the family
- Support inclusion in meaningful community activities and contexts
- Support youth inclusion and involvement in community activities with their family as well
- Strengthen the collective activity of community members through forming neighbourhood groups and community organizations that monitor, care, and advocate for the well-being of youth



Autism Mental Health Literacy Project (AM-HeLP) Group. (2021). *Mental Health Literacy Guide for Autism*. Retrieved from:

<https://www.yorku.ca/health/lab/ddmh/am-help>